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AUTHOR Ingram, Debby
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ABSTRACT

Basic information about respite care for individuals with disabilities and their families is presented in a question-and-answer format. The following questions are addressed: "What is respite?"; "Who needs respite services?"; "Who provides respite services?"; "What kinds of services are provided?"; "How are respite services funded?"; "Are there eligibility requirements for respite services?"; "How do families benefit from respite services?"; "How do families obtain services?"; "What can I do to get a respite program started in my community?"; "Are respite care providers required to be licensed?"; and "Can I use a regular child care program for respite?" Four organizational resources and four references are provided. (DB)

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Q&A

RESPITE CARE

By Debby Ingram, Research Associate, Family Support Project, "Strengthening American Families Through National and Grassroots Support"

What is respite?

Respite usually refers to short term, temporary care provided to people with disabilities in order that their families can be relieved from the daily routine of caregiving. Unlike day programs, respite services may sometimes include overnight stays for an extended period of time. Respite care enables families to take vacations, or just a few hours of time off. Respite is often referred to as "a gift of time."

Who needs respite services?

Parents may be reluctant to use a respite program. They may even question the need for this type of service. Valdivieso (1989) recommends that families of children with mental retardation and other disabilities ask themselves these questions to determine if respite services are necessary:

- Is it difficult to find temporary care for my child?
- Does caring for my child interfere with scheduling appointments or with personal projects?
- Is it important that my spouse and I enjoy an evening alone together, without the children?
- If I had appropriate care for my child with a disability, would I use the time for a special activity with my other children?
- Am I concerned that in the event of a family emergency there is no one with whom I would feel secure with to leave my child?
- Would I feel comfortable having a trained, caring respite provider care for my child?
- Do I avoid going out because I feel I would be imposing on the family and friends who care for my child?

If family members answer "yes" to any of these questions, the family may very well benefit from respite care services.

Who provides respite services?

Most programs are managed by affiliates or chapters of national organizations such as The Arc and the Easter Seal Society. United Cerebral Palsy Associations provide a unique respite service in cooperation with local hotels. Many other programs are provided by local organizations such as churches, schools and other non-profit groups. Sometimes families arrange for care with neighbors or other people they know.

What kinds of services are provided?

Services are provided in many ways depending on the provider, the needs of the family and available funds. Some respite programs send a caregiver to the family's home. Others require that the individual come to a day care center or respite group home.

In some programs the care is provided by a host family which also has a family member with a disability. They usually provide respite services in exchange for the same services from another family. These programs are called "host family" or exchange programs.

Emergency respite services are also important. Parents need to be able to access services on short notice in the event that an unexpected family emergency occurs.

How are respite services funded?

Many programs receive public funding for their services. Some charge fees on a sliding scale based on the family's income. Other programs may be operated by non-profit organizations which receive funding from donations or other sources. Many programs must use a combination of funding sources in order to meet their financial needs.

Are there eligibility requirements for respite services?

In almost all state-funded programs, eligibility is based on the child's age and disabilities. Family income is also usually considered.

In a 1990 survey of 111 respite care programs, 97 programs provided services for children as young as newborns. Seventy-one programs provided services until age 22, 11 programs provided services only for young children and 29 programs provided care throughout the child's life (US/GAO).

How do families benefit from respite services?

The benefits are numerous, but not always obvious. Providing a break in the daily routine may help parents avoid burnout, stress and fatigue. Periodic respite care can help families relax for a while and come back revitalized and better able to care for their son or daughter.

Respite care not only provides caregivers a break, but also gives the child or other family member a change in his or her daily routine. It can provide the child opportunities to build new relationships and move toward independence (Valdivieso, 1989).

How do families obtain services?

Accessing the system can be difficult, but not impossible. Contact your state's planning council on developmental disabilities, community mental health/mental retardation center or a local chapter of The Arc and ask them to refer you to a program. Many programs have been developed when families made their needs known to community mental retardation advocates and service providers.

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Many respite programs have been developed by parents to meet their own needs. For example, Jody and His Friends, Inc. is a respite program started in California by a couple who were unable to find respite services. These parents joined with the Vallejo-Benica chapter of The Arc and developed an in-home respite program. Jody and His Friends, Inc. was such a success that it is now an agency of the State of California Department of Developmental Services (Valdevieso, et al., 1989).

What can I do to get a respite program started in my community?

A good way to get started is to first determine what kinds of services are needed.

- Ask other parents in the community about their needs for respite services: Do they need or want in-home care, or could care be provided at a community center? Determine if overnight or weekend care is needed.
- Find a respite provider in another community that already provides these types of services and ask them how they started their program.
- Contact state licensing agencies to find out licensing requirements for operating a respite program.
- Find an organization in your community that might be interested in helping you start a program. Churches, schools, local Red Cross chapters and disability organizations may provide the personnel, experience and/or financial resources necessary to start or operate a new program.

Are respite care providers required to be licensed?

Of the 111 programs surveyed, 91 had eligibility or licensing requirements that addressed the areas of age, training, education and licensing or certification by a profession or specialty. To ensure that quality services are being provided, 91 programs were required to 1) maintain records of services, 2) provide follow-up to families that have been served, and 3) pass site inspections where services are provided (US/GAO).

Parents should make the final determination about respite providers. They should examine various aspects of the program such as staff training, monitoring by outside agencies, safety and health measures, parental involvement in decision-making and other related areas. The state or local licensing office should be able to answer questions about complaints against a specific program and whether that program has consistently met all licensing requirements.

Some questions to ask about a respite care program are:

- How are care providers screened?
- What is the training and level of experience of the care providers?
- Will care providers need additional training to meet specific family needs?
- How, and by whom, are the care providers supervised?
- What happens during the time the children are receiving services? Are there organized activities? How are meals handled?
- Does the program maintain current information about each child's medical and other needs? Is there a written care plan?
- What procedures does the program have for emergencies?
- Can parents meet and interview the people who care for the children?
- How far ahead of time do parents need to call to arrange for services?
- Are families limited to a certain number of hours of services?
- Does the program provide transportation?
- Can the provider take care of brothers and sisters as well?
- What is the cost of services? How is payment arranged? (Karp, et al., undated).

Can I use a regular child care program for respite?

Many day care centers in the community offer "drop in" services for a day or sometimes for an extended period. To use drop in services, parents must often give some advance notice and complete the required paperwork, such as the child's medical history and emergency contact persons.

With the passage of the Americans with Disabilities Act (ADA), these programs must now make a reasonable attempt to provide the same services for a child with a disability. The ADA mandates that public accommodations, including child care centers, make reasonable modifications in policies, practices and procedures in order to accommodate individuals with disabilities. However, child care centers and other entities covered under the ADA are not required to modify their policies and practices if it would "fundamentally alter" the nature of their services.

If a child care center restricts its services to minor children, parents who have an adult child with mental retardation may have to consider other respite options. In addition, centers may not have to provide certain services such as those involving skilled medical procedures or on-site nursing, because the provision of these services could be considered a "fundamental alteration" or a service outside a child care centers' area of specialization (DOJ, July 1991).

For further information about child care and the Americans with Disabilities Act, refer to: The Arc's *Q&A* on child care settings and the Americans with Disabilities Act (May, 1992).

The following are just a few of the many resources for further information about respite:

The Arc Family Support Project, 500 East Border, Suite 300, Arlington, Texas 76010. Phone: 1-800-433-5255.
Texas Respite Resource Network, P.O. Box 7330, Station A, San Antonio, Texas 78207-3198. Phone: (512) 228-279
Georgia Respite Network, Room 620, 878 Peachtree St. NE, Atlanta, Ga. Phone: (404) 894-5790.
Maine Respite Project, 159 Hogan Road, Bangor, Maine 04401. Phone: (207) 941-4400.

References:

Federal Register: 28 CFR Part 35, *Nondiscrimination on the Basis of Disability in State and Local Government Services.* Final Rule. Number 1512-91, (July, 1991). Washington, D.C.: Department of Justice, Office of the Attorney General, (DOJ).

Karp, N., Hubbell, R., Licwinko, M., DeWolfe, J., Johnson, B., Jeppson, E., McGonigel, M., Thomas, J. & Guadagno, N., *Respite Care: A Guide for Parents* (undated). Washington, D.C.: CSR, Incorporated and Association for the Care of Children's Health.

Respite Care: An Overview of Federal, Selected State and Private Programs. Report number GAO/HRD-90-125, (September, 1990). Washington, D.C.: United States General Accounting Office, (US/GAO).

Valdivieso, C., Ripley, S., Kupper, L., & Horne, R., NICHY News Digest, *Respite Care: A Gift of Time.* Number 12, 1989. Washington, D.C.: Interstate Research Associates.

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